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PRACTICE

GUIDELINES

Management of autism in children and young people: summary of NICE and SCIE guidance

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This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists.

Autism occurs in approximately 1% of children and young people,¹ though the diagnosis is made less commonly in girls² and anyone with severe intellectual disability.¹ It is one of the most important causes of lifelong disability, with support and lost productivity costs estimated at more than £28bn (£32bn, \$43bn) annually in the UK.³ Individual presentations vary widely, as do associated functional impairments, but the core features of autism are persistent impairment in reciprocal social interaction and social communication and restricted, repetitive patterns of behaviour, interests, or activities. These features occur whether or not the individual has an intellectual disability and are typically present in early childhood, though they may be masked by parental support or compensations. Intellectual disability, language impairment, academic deficits, and movement disorders are common,⁴ and mental and behavioural disorders are found in up to 70%.⁵ The presence of all these factors, as well as sensory sensitivities, constipation, sleep and eating problems, and behaviour that challenges, add considerably to the impact on the child or young person, their family, and professionals in health and social care and education.

This article summarises the most recent joint recommendations from the National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) on managing autism in children and young people.⁶

Recommendations

NICE recommendations are based on systematic reviews of the best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are given in *italic* in square brackets.

Access to health and social care services

- Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis. [*Based on qualitative studies of the experience of care and the experience and expert opinion of the Guideline Development Group (GDG)*]

Organisation and delivery of services

- The assessment, management, and coordination of care for children and young people with autism should be provided through local, specialist, community based, multidisciplinary teams—which should include professionals from health, mental health, learning disability, education, and social care services in line with NICE clinical guidance on autism in children and young people (CG128)⁷ and on autism in adults (CG142).⁸ [*Based on qualitative studies of the experience of care, a review of*

NICE guidance on autism, and the experience and expert opinion of the GDG]

Knowledge and competence of health and social care professionals

Health and social care professionals working with children and young people with autism in any setting should receive training in autism awareness and skills in managing autism, including

- The nature and course of autism
- The nature and course of behaviour that challenges in children and young people with autism
- Recognition of common coexisting conditions, including
 - Mental health problems such as anxiety and depression
 - Physical health problems such as epilepsy
 - Sleep problems
 - Other neurodevelopmental conditions such as attention-deficit/hyperactivity disorder (ADHD)
- The individual's experience of autism and its impact on him or her
- The impact of autism on the family (including siblings) or carers
- The impact of the social and physical environment on the individual
- How to assess risk (including self harm, harm to others, self neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- The changing needs that arise with puberty (including the individual's understanding of intimate relationships and related problems that may occur, such as misunderstanding the behaviour of others)
- The importance of key transition points, such as changing schools or health or social care services
- How to provide individualised care and support and the need for consistency of approach across home, school, and other settings
- Skills for communicating with a child or young person.

[Based on qualitative studies of the experience of care and on the experience and expert opinion of the GDG]

Making adjustments to the social and physical environment and processes of care

- Take into account the physical environment in which the individual is supported and cared for and minimise any negative impact by making reasonable adjustments or adaptations to the setting, including
 - Visual supports (such as words, pictures, or symbols at a level that is meaningful for the person)
 - Sensory challenges such as colour of walls and furnishings, lighting, or noise levels
 - Amount of personal space given.

[Based on qualitative studies of the experience of care and the experience and opinion of the GDG]

Interventions for the core features of autism

- For the core features of autism, consider a specific social communication intervention that includes play based

strategies with parents, carers, and teachers to increase joint attention, engagement, and reciprocal communication in the child or young person. Strategies should

- Be adjusted to the individual's developmental level
- Aim to increase the parents', carers', teachers', or peers' understanding of and sensitivity and responsiveness to the individual's patterns of communication and interaction
- Include techniques of therapist modelling and video interaction feedback
- Include techniques to expand the individual's communication, interactive play, and social routines.

The intervention should be delivered by a trained professional. For preschool children, consider parent, carer, or teacher mediation. For school aged children, consider peer mediation. *[Based on low to moderate quality randomised controlled trials for caregiver and teacher mediated interventions and very low quality randomised controlled trials for peer mediated interventions]*

- Do not use antipsychotics, antidepressants, anticonvulsants, and exclusion diets (such as gluten-free or casein-free diets) to manage the core features of autism because the balance of risks (especially with anticonvulsants and exclusion diets) and benefits did not favour their use. *[Based on moderate to very low quality randomised controlled trials for antipsychotics, antidepressants, and anticonvulsants; low to very low quality randomised controlled trials for exclusion diets; and the experience and expert opinion of the GDG]*

Interventions for autism that should not be used in any context

- Do not use secretin, chelation, or hyperbaric oxygen therapy to manage autism in any context because there is no clear evidence that these are effective and because there is harm associated with their use. *[Based on moderate to very low quality randomised controlled trials for secretin, low to very low quality randomised controlled trials for chelation and hyperbaric oxygen therapy, and the experience and expert opinion of the GDG]*

Interventions for behaviour that challenges

- In routine assessment and care planning, assess factors that may increase the risk of behaviour that challenges, including
 - Impairments in communication that may result in difficulty understanding situations or expressing needs and wishes
 - Coexisting physical disorders (such as pain or gastrointestinal disorders), mental health problems (such as anxiety or depression), and other neurodevelopmental conditions (such as ADHD)
 - The physical environment, such as lighting and noise levels
 - The social environment, including home, school, and leisure activities
 - Changes to routines or personal circumstances
 - Developmental change, including puberty
 - Exploitation or abuse by others
 - Inadvertent reinforcement of behaviour that challenges
 - The absence of predictability and structure.

[Based on the experience and expert opinion of the GDG]

- If no coexisting mental health or behavioural problem, physical disorder, or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer a psychosocial intervention (informed by a functional assessment of behaviour) as a first line treatment. [Based on the experience and expert opinion of the GDG]
- Consider antipsychotic medication for managing behaviour that challenges when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour. Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist, who should
 - Identify the target behaviour
 - Decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact
 - Review the effectiveness and any side effects of the medication after three to four weeks
 - Stop treatment if there is no indication of a clinically important response at six weeks.

[Based on low to moderate quality randomised controlled trials for efficacy of antipsychotic medication and the experience and expert opinion of the GDG for prescribing and monitoring considerations]

Interventions for sleep problems

- If the individual has a sleep problem offer an assessment that identifies
 - What the sleep problem is (for example, delay in falling asleep, frequent waking, unusual behaviours, breathing problems, or sleepiness during the day)
 - Day and night sleep patterns, and any change to those patterns
 - Whether bedtime is regular and what the sleep environment is like
 - Presence of comorbidities, especially those that feature hyperactivity or other behavioural problems
 - Levels of activity and exercise during the day
 - Possible physical illness or discomfort
 - Effects of any medication
 - Individual factors such as emotional relationships or problems at school
 - The impact on parents, other family members, or carers.

[Based on the experience and expert opinion of the GDG]

Families and carers

- Offer families (including siblings) and carers an assessment of their own needs, including whether they have
 - Personal, social, and emotional support
 - Practical support in their caring role, including short breaks and emergency plans
 - A plan for future care for the child or young person, including transition to adult services.

[Based on qualitative studies of the experience of care and the experience and opinion of the GDG]

Transition to adult services

- For young people aged 16 or older whose needs are complex or severe, use the care programme approach⁹ in England (care and treatment plans in Wales) to coordinate their needs and as an aid to transfer between services.
 - Involve the young people in the planning and, where appropriate, their parents or carers
 - Provide information about adult services to the young people, and their parents or carers, including their right to a social care assessment at age 18.

[Based on the experience and opinion of the GDG]

Overcoming barriers

Currently, widespread inconsistency in access to and provision of care and effective interventions (for autism and for physical and mental health problems) are potential challenges to guideline implementation. However, establishing local autism strategy groups and multidisciplinary autism teams should help to resolve this problem and improve access to care. Moreover, in differentiating interventions for the core features of autism, associated problems, and coexisting physical and mental health problems, the guideline will help people access effective treatments and prevent them from being offered ones that are ineffective or harmful. Provision of social care is also variable and sometimes inadequate; to help overcome this challenge, the guideline advises integrating health and social care within the multidisciplinary autism team and recommending social support for the child and his or her parents.

The members of the Guideline Development Group were Gillian Baird (chair), Tim Kendall (facilitator), Nick Gould (co-facilitator), Odette Megnin-Viggars (systematic reviewer), Virginia Bovell, Carole Buckley, Lucy Burt (research assistant), Tony Charman, Jonathan Green, Patricia Howlin, Glenys Jones, Ann Le Couteur, Katherine Leggett (project manager), Robin Mackenzie, Ifigeneia Mavranzouli (senior health economist), Sabrina Naqvi (project manager), Barbara Parker, Emily Simonoff, Stephen Simpson, Vicky Slonims, Alison Stewart, Sarah Stockton (senior information scientist), Katy Strudwick, Clare Taylor (senior editor), and Gabriel Whittingum.

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Further information on the guidance

There is wide variation in access to and quality of intervention services despite recent clinical guidance in the UK.¹⁰⁻¹² Many families report that they experience difficulties in getting a diagnosis of autism confirmed, delays in accessing specific interventions, a lack of understanding about the way autism affects an individual, and problems accessing help for physical and mental health problems and behaviour that challenges.¹³ Professionals may not recognise that additional mental and behavioural problems are distinct disorders and therefore may not offer effective treatments (for example, cognitive behavioural therapy for anxiety and psychostimulants for ADHD symptoms). Young people with intellectual difficulties and their parents may have particular challenges accessing skilled help through generic services.

The level and form of social care provided are also highly variable and often determined by historical patterns of service development rather than by needs or evidence. Surveys indicate that families feel inadequately provided with services such as occupational therapy, respite care and short breaks, information and advocacy, and preparing for the transition to adult services.¹⁴ Social care services for children and young people are often generic, without sufficient understanding of the distinct complexities of autism: eligibility criteria for services may lack relevance, and intervention may be available only when a crisis has been reached.¹⁵

Methods

This guideline was developed by the National Collaborating Centre for Mental Health using NICE's guideline methods (<http://publications.nice.org.uk/the-guidelines-manual-pmg6>). The guideline review process involved comprehensive and systematic literature searches to identify relevant evidence for the clinical and economic reviews, with critical appraisal of the quality of the identified evidence. A multidisciplinary team of health and social care professionals from psychiatry, psychology, paediatrics, speech and language therapy, occupational therapy, general practice, nursing, social work, and education, as well as representatives of service users and carers (the GDG), was established to review the evidence and develop the subsequent recommendations. The guideline then went through an external consultation with stakeholders. The GDG considered the stakeholders' comments, reanalysed the data where necessary, and modified the guideline as appropriate.

NICE has produced three different versions of the guideline: a full version; a summary version known as the "NICE guideline"; and a version for children and young people with autism, their parents and carers, and the public. All these versions, as well as a pathway, are available from the NICE website (<http://guidance.nice.org.uk/CG170>). Updates of the guideline will be produced as part of NICE's guideline development programme.

Areas for future research

- The value of a key worker approach (which is defined by protocol and delivered in addition to usual care)—for children and young people with autism in terms of parental satisfaction, functioning and stress, and child psychopathology.
- The clinical and cost effectiveness of
 - Group based parent training intervention (compared with treatment as usual) for parents or carers of children and young people with autism in reducing early and emerging behaviour that challenges in the short and medium term
 - Sleep hygiene intervention or melatonin to treat problems with sleep onset, night waking, and reduced total sleep in children aged 4-10 years with autism
 - Pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism.
- The effectiveness of comprehensive early interventions that combine multiple elements and delivery by parents and teachers in managing core autism symptoms and coexisting difficulties in children of preschool age.

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